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# The increased need for palliative cancer care in Sub-Saharan Africa

Willemijn Y. van der Plas [a, b], Stan Benjamens [a, b], Schelto Kruijff [a, b, *]

[a] Department of Surgery, University Medical Center Groningen, Groningen, the Netherlands
[b] Nkhoma Mission Hospital, Nkhoma, Malawi

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ABSTRACT

Although palliative care as a discipline in high income countries is maturing, it is still somewhat in its infancy in sub-Saharan Africa, an area where this type of care is needed the most: more than 80% of people in urgent need of palliative care live in low- and middle-income countries (LMICs). We will describe why the development of palliative care in LMICs is increasingly essential, and how it is currently still underdeveloped. In this manuscript, we discuss the challenges in organizing palliative care in LMICs in regard to the four WHO palliative care pillars: policy, education, medication, and implementation. We will illustrate how several Sub-Saharan African countries are increasingly able to provide palliative care analyzed in terms of these pillars. Ultimately, scientific research and cost-effectiveness analyses of well-developed palliative programs, should encourage both local and international governments and authorities to provide more capital and human recourses for palliative care in the future.



## Introduction

According to the World Health Organization (WHO), the ultimate goal of palliative care is to improve the quality of life of both patients and their family in the event of serious suffering from a life-threatening condition. Preventing and alleviating suffering is achieved through early identification and careful assessment of pain and other problems of a physical, psychosocial and spiritual nature [1]. Despite its relevance, well developed palliative medicine, appears to be only available in countries where the basic health care has been well established. Cynically, more than 80% of people in urgent need of palliative care live in low- and middle-income countries (LMICs) where basic health care is less well developed [2]. Unfortunately, in these LMICs, approximately 80% of newly discovered cancers are no longer curable at the time of diagnosis and access to basic palliative care and medication-based pain relief is extremely limited [3,4]. It is estimated that in LIMCs 20 million people die each year with severe pain that could have been alleviated with morphine. For another 28 million patients who did not die, morphine to combat severe pain was not accessible. Only 3.6% of available opioid pain killers are available in LIMCs and only 0.03% in low-income countries [2]. In the near future, the total number of patients who require palliative care at some point in their lives will grow significantly and is likely to double [5]. Although palliative care as a discipline in high income countries is maturing, it is still relatively in its infancy in sub-Saharan Africa an area where it is needed the most. In this short report we will describe why the development of palliative care in LMICs is increasingly essential, and how it is currently still underdeveloped. We will outline the challenges, both for care seekers and caregivers, for several Sub-Saharan African countries including Malawi, a country where the authors of this manuscript have worked. Therefore, we reviewed the literature. A narrative description is organized along the path of the four pillars to improve palliative care, as outlined by the WHO [6].

### *Policy*

Inadequate policymaking is the first and possibly the main obstacle in LMICs, due to unstable governments and widespread corruption. Just like in high-income countries, evidence about the effectiveness of palliative care remains pivotal to secure adequate funding from governments and non-governmental organizations (NGOs). Cost-effectiveness analyses in South-Africa showed that by organizing outpatient palliative care, half of the costs can be saved due to a reduced number of admissions [7]. To allow governments to understand the effect of palliative care, adequate registration and monitoring are therefore necessary, which is challenging with the absence of any form of electronic patient records. Our literature

* Corresponding author. Hanzeplein 1, 9700 RB, Groningen, P.O 30.001, the Netherlands.
*E-mail address:* s.kruijff@umcg.nl (S. Kruijff).

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search showed that most governments seem to have some form of policy on the management of palliative care in their country (Table 1). National associations to organize and improve palliative care have been established in the last decade [8]. For instance, In Uganda and Botswana, governmental palliative care policies became part of the 5-year strategic plans for their general health care [9,10]. For other Sub-Saharan African countries, the degree of influence these palliative care associations have on governments and other policy makers is still unclear and might be limited.

*Education*

Incorporating palliative care in the medical and nursing education is essential for the implementation of palliative care programs. Current medical training for medical and clinical officers, and nurses is still primarily focused on treating infectious diseases and mother and childcare. Initiatives have been launched for the development of expertise on non-communicable diseases such as cancer and chronic heart disease, diabetes mellitus, and malignant diseases, but are still in its infancy. Following the trend in high-income countries, the focus will have to shift towards providing comfort and maintaining quality of life in palliative cancer patients. With education it is needed to force a change in mindset for healthcare workers, from a treatment perspective towards an open conversation about the impact of a chronic life threatening illness and subsequent shared-decision making. With a general view of the past, doctors in Sub-Saharan African countries are not typically the bearer of bad news. They are used to avoid open communication about this difficult topic and patients do not want to have taken away their hope of living by the news of an incurable disease [11]. This must be considered during training, and in collaboration with the local health practitioners appropriate communication skills should be taught with on the one hand giving clear information to the patients while on the other hand keeping the local culture and communication habits in mind. While Kenya, Uganda and Botswana initiated post-graduate training programs for palliative care, South Africa is leading the way with a well-established post-graduate and research program on palliative care [10,12,13]. Mentorship programs or the assistance of the Africa Palliative Care Association (APCA), as in Botswana, could be of assistance in improving palliative care education in those countries in which a broad medical education is scarce [9]. Support of international oncology and palliative care organizations should go to local sustainable programs, with short local training initiatives and web-based seminars.

Next, extensive information will also be necessary for patients and their families. Taboos are found in various forms, such as women bathing men and intimate care for close relatives, which form serious obstacles in taking care during the palliative phase [14]. Also, patients that are dying now often come to the hospital in hope of some miraculous cure. In consultation with them, more attention will have to be paid to the required care at home and the accompanying expectations and fears that go along with such pathway. Home care requires reorganization of family life, findings ways to combine care for close relatives and children.

*Availability of medication*

Availability of medication is an international problem, where efforts from local governments will have to be supported by international organizations. At present there is a major shortage of medication for pain relief. The high prices of the medicines, up to 30 times higher prices in LMICs compared to high-income countries, make palliative care largely dependent on financial donations [15].

**Table 1**
Overview of palliative care in eight Sub-Saharan Africa countries.

| | Policy | Education | Medication | Implementation |
|---|---|---|---|---|
| Botswana [9] | Botswana Hospice and Palliative Care Association & 5-year national palliative care strategy - home-based care programs | Palliative care training in collaboration APCA & Broad coverage of palliative care in medical education. Wide-spread lack of patient awareness | National pain management guidelines & Oral morphine prescription exclusive for MOs | Three hospices providing palliative care & insufficient capacity |
| Ethiopia [22] | Palliative Care Association for Ethiopia & 50% healthcare coverage within walking distance to healthcare facility | No specific palliative care education | Limited access to oral morphine & Subsidised chemotherapeutics (often not available) | Two regional NGOs are licensed palliative care institutions (±60 patients) |
| Kenya [12] | Kenya Hospitals and Palliative Care Association & National Palliative care Guidelines | Higher diploma for palliative care | Centralized production of oral morphine by the Kenya National Hospital | Palliative care units, linked with local hospices & Palliative care in government hospitals |
| Malawi [23] | Palliative care association Malawi & Lack of national guidelines | No specific palliative care education | Lack of available drugs due to insufficient funding | Locally organized palliative care teams, funded by NGOs & Workforce remains sparse. |
| Nigeria [17] | Hospice and Palliative Care Association of Nigeria & Lack of national guidelines | Undergraduate course at the college of medicine & Poor patient awareness | Medical Regulation and Drugs Policy & Government controlled distribution – with strict regulation | Government organized palliative care in all tertiary health centres |
| Rwanda [20] | National Standards and Guidelines for the Provision of Palliative Care & National Palliative Care Policy | Palliative care training in collaboration the University of Edinburg & Clinical mentoring in palliative care | Ministry of Health opioids production facility & Government controlled importation and distribution | Palliative care in district hospitals & Home-based palliative care & Aim for universally accessible palliative care |
| Senegal [24] | Senegalese Association for Palliative Care | No specific palliative care education | Limited access to morphine & recent start with centralized production of oral morphine | No outpatient services for palliative care |
| South Africa [13] | Hospice and Palliative Care Association since 1987 | Mentorship programme & Post-graduate palliative care training and research programmes | Wide-spread availability | 102 palliative care units & Focus on home-based palliative care |
| Uganda [10] | Palliative Care Association of Uganda & 5-year strategic health plan - including palliative care as essential service | One-year fulltime diploma in clinical palliative care with the IHPCA & 3-year bachelor degree with a foreign university | Guidelines on pain control and use of narcotic drugs & Nationwide free distribution of oral morphine prescribed by MOs, COs and MAs | Local and regional palliative care teams |

PCA = Africa Palliative Care Association; IHPCA = Institute for hospice and palliative care in Africa.
= Medical officer; CO = Clinical Officer; MA = Medical Assistants; NGO = non-Governmental organizations.

Where first step pain medication (e.g. paracetamol) is still available and affordable, second step (e.g. tramadol) and third step (e.g. morphine) pain medication are not affordable for the majority of patients. Large-scale and central purchasing of medication is a possible solution for high prices and poor availability [16]. Government controlled distribution in Nigeria decreases the abuse of opioids but limits readily available access for patients in need [17]. A similar dilemma lies in who is authorized to prescribe morphine. Opioids will not be accessible for every patient in need as often it can only be prescribed by medical officers (registered doctors), as seen in Botswana and Nigeria [9,17]. Yet abuse and misuse is feared when opioids are readily accessible. So-called 'opiophobia' makes governments hesitant in allowing widely available morphine in attempt to decrease the ongoing opioid epidemic in Africa [18]. Uganda however, has shown an efficient morphine regulation, storage, prescribing and consumption program, without evident abuse [19]. Regulated adequate supply at national level, on-going support by district health authorities monitoring the quality of the service, nurse training, and continuous food supply were thought to be contributory to a successful pain relief program [19]. In Rwanda, international collaborations and clear governmental goals resulted in the successful implementation of a government controlled opioids production facility [20,21].

*Implementation*

Implementation requires long-term commitment from all parties involved and substantial support for continuous evaluation and improvement of the established system. Providing training to the health care workers and making funds available for the purchase of the necessary medication and transport can lead to major changes in the short term. In addition, palliative care must become part of all the domains described: *(1)* the government will have to follow a consistent course for the reimbursement and support of palliative care. *(2)* As stated, education about palliative care will have to be embedded in the standard curriculum of the different medical courses and training. Furthermore, a mentoring program could be set up to guarantee the quality of the various palliative care teams. *(3)* The responsibility for affordable medication might lie with the pharmaceutical industry and international organizations such as the World Health Organization (WHO). Yet, in the medium and long term, a system of medication procurement will have to be initiated from the local government. Currently, lack of financial and human resources still restricts nationwide implementation of appropriate palliative care in most Sub-Saharan African countries.

## Conclusion

In LIMCs, there is a large discrepancy between the demand and the supply of palliative care. Information with regard to the accessibility and effectiveness of palliative care in the Sub-Saharan African region is scarce. Lack of adequate infrastructure makes evaluation of current palliative care initiatives difficult. It is unclear what the best organizational method of palliative care in sub-Saharan Africa would be. While the knowledge and possibilities to provide assistance to these patients are severely lagging behind, the need for adequate support for terminal ill patients is increasing fast. Registration and audits of small palliative care initiatives should generate solid evidence that shows policy makers the need for palliative care on a larger scale. By showing the cost-effectiveness of well-developed palliative programs, governments and authorities are encouraged to provide more capital and human recourses for palliative care in the future. Furthermore, the training and education program for health care providers must be adapted to the changing epidemiology of non-communicable diseases and more attention should be paid to palliative medicine.

Above all, the availability of pain medication urgently needs improvement. While national initiatives have established palliative care and cancer associations, worldwide action should bring implementation to the next level. Fighting the pain crisis, cannot longer be a battle for Sub- Saharan African countries on their own, but should be a joint effort of international community, NGO's, and the pharmaceutical industry.

## Declaration of competing interest

The authors declare no conflicts of interest.

## CRediT authorship contribution statement

**Willemijn Y. van der Plas:** Conceptualization, Investigation, Writing - original draft. **Stan Benjamens:** Conceptualization, Investigation, Writing - original draft. **Schelto Kruijff:** Conceptualization, Writing - review & editing, Supervision.

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